

PUBLIC AWARENESS ON THE CHARACTERISTICS OF CHILDREN WITH AUTISM IN SELANGOR (Kesedaran Umum Terhadap Karakter Kanak-Kanak Autism Di Selangor)

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Abstrak

Tujuan kertas kerja ini adalah untuk mengkaji tahap kesedaran masyarakat terhadap ciri-ciri kanak-kanak autistik di Selangor. Bagi mereka yang tidak faham tentang spektrum autisme, ia mungkin sukar untuk membezakan antara tingkah laku autistik dan salah laku kanak-kanak biasa. Kanak-kanak autistik seringkali dilihat sebagai kanak-kanak yang bermasalah. Manakala ibu bapa kanak-kanak autistik dilihat sebagai ibu bapa yang tidak dapat mengawal anak-anak mereka, atau ibu bapa yang mempunyai anak-anak yang mempunyai masalah disiplin. Kurangnya kesedaran masyarakat mengenai spektrum autisme memberi kesusahan kepada keluarga, terutama mereka yang mempunyai kanak-kanak autisme yang menunjukkan tingkah laku letupan amarah di tempat awam. 250 salinan borang soal selidik berstruktur diedarkan secara rawak kepada responden di Lembah Klang. Dapatan kajian menunjukkan bahawa kebanyakan responden maklum tentang istilah autisme secara umum tetapi mereka tidak memahami secara terperinci ciri-ciri sebenar kanak-kanak autisme. Hasil kajian ini dijangka akan meningkatkan kesedaran masyarakat tentang ciri-ciri, sikap dan tingkah laku kanak-kanak autistik, dan dengan itu diharapkan masyarakat akan lebih peka dan simpati kepada kanak-kanak ini dan bersedia untuk membantu mereka dan keluarga mereka dengan penuh keikhlasan.

Kata Kunci: Kesedaran masyarakat, kanak-kanak autistik, Selangor

Abstract

The aim of this paper is to provide a preliminary view about public awareness towards the characteristics of children with autism in Selangor. For those who do not understand about autism spectrum, it may be difficult to distinguish between autistic behavior and misbehavior of typical children. Unfortunately, these children are always perceived as spoiled children by public. Parents of autistic children are seen as parents who cannot control their children, or parents who have children with disciplinary problems. Lack of awareness of autism spectrum is another hardship on families, especially those who have children with autism that show behavior of temper tantrum. 250 copies of structured questionnaires distributed randomly to residents within the Klang Valley. The findings indicated that most of the respondents are familiar with the term autism but they still do not understand in details the characteristics of children with autism. The outcome of this study is expected to increase public awareness about the characteristics of autistic children. It is expected that when more people know about the characters, attitudes and behaviors of autistic children, hopefully people will be more alert and feel sympathy to these children and are willing to help them and their families with full sincerity.

Keywords: Public awareness, children with autism, Selangor

1.0 INTRODUCTION

Autism or autism spectrum disorder (ASD) is a developmental disorder that gives significant impact on people's lives. Raising a child with autism sometimes can be very challenging for parents, guardians and families (Bashir et al. 2014). Parents need to go through hardships with patience in trying to give the best to their autistic children. This usually involves the feelings of distress, painful, frustration, high expenses (Jiar & Xi, 2012) and time as well as energy to deal with autistic children that are so different and unique. Children with autism are often accompanied by extremely disruptive antisocial behavior. They tend to act aggressively such as biting, hitting, kicking on others and/or themselves (Dominick et. al., 2007), which can add more pressure to parents or guardians. Meanwhile, because of the misunderstanding towards autistic behavior, some people discriminate or even sometimes show negative attitudes to children with autism and their families.

Although awareness among Malaysians has improved but still much more research is needed to ensure people get a better understanding about autism (Jasni, 2011). Study on public awareness on children with autism is essential in reducing discrimination and stigmatization and creating a sense of responsibility among people towards autistic children and families. The information about Autism Spectrum Disorders (ASDs) is necessary for public to make them come forward to provide assistance to children with autism and their families.

This paper aimed to provide a preliminary insight into the awareness among people particularly in Selangor about the characteristics of children with autism. The findings can be used for other studies in the future. The aim is to increase public understanding about the actual characteristics of children with autism in the hope that it will change the negative perception among people who never knew about ASDs.

2.0 STATEMENT OF THE PROBLEM

At one time, the government, counselling, psychologists and teachers are said as not giving enough attention on the issues of autism and there are many gaps in public understanding of autism (Audu & Egbochuku, 2010). In addition, although people have heard about autism but they do not really understand about autism spectrum in detail (Meiriawan et. al. 2017).

In Malaysia, it is still difficult for people to get good information, exposure or experience of people with ASDs (Jasni, 2011). This can lead to negative attitudes (Selamat Widasmoro Neni et. al., 2010) from public to the families and individuals with autism. In many cases, families experienced high levels of stigmatization in society because of their autistic children. Families often discovered that public reaction to them was stereotypical and negative (David E.Gray, 2002). Parents or families of children with autism tend to have higher levels of stress.

A study conducted by David E. Gray (2002) showed that most parents, especially the mothers experienced the stigma that generates the feelings of extreme embarrassment. Parents always noticed the hostile stares from others and their competences are often judged whenever their children show inappropriate behavior in public. Parents of aggressive children who like to disturb others and provoke a larger reaction more likely to experience stigma from parents who have passive children.

Aware of the high pressure and distress levels of parents or guardians of these children, the need to help reduce their stress is important. Families with autistic children always have problems, particularly in coordinating care and receive support from others. Therefore, efforts to improve the understanding of autism spectrum should be focused not only to parents or guardians of autistic children but also to anyone in this world.

Since it was difficult to find literature about the awareness of Malaysians on autism, therefore, this study was conducted to assess public awareness towards children with autism in the state of Selangor, Malaysia. This was considered as the starting point for other studies to focus on someone other than parents, relatives or guardians of children with autism.

3.0 OBJECTIVES OF THE STUDY

It is very important to educate public about autism spectrum (Danielle, 2012). Although, there are many studies of autism have been conducted by various researchers, but most have focused only on children with autism and their parents or families. This study was conducted to provide an initial overview about

the awareness among the general public in Selangor towards the characteristics of children with autism. Findings from this preliminary study are significant to some parties in Malaysia including health care teams, NGOs, media, government, professionals, educators and parents as well as the public. By raising awareness, it is expected that general public will no longer have negative impressions towards autistic individuals and families.

This awareness is believed can change the scenario of ignorance about autism and lead towards a better life for autistic individuals and their families. The more people know about autism, the higher the level of tolerance of people towards children with autism, and families of autistic individual will get more support from the public. A better understanding of the public about autism can contribute to reduce the stigma experienced by parents of autistic children (Gray, 2002). In addition, this paper also listed some of the common characteristics of autistic children based on what have been described in literature.

4.0 REVIEW OF LITERATURE

The term of autism was first introduced by Eugen Bleuler, the Swiss psychiatrist to define the symptoms of schizophrenia in 1910. Autism was first studied in depth since 1938. Then in 1943, another doctor, Leo Kanner described autism as a developmental disease and it is present from birth (Meiriawan et. al. 2017).

Table 1.0: List Of The Common Characteristics Of Autism

Author, Year	Characteristics
Danielle, 2012	Individuals with autism may experience: Learning disabilities, Language problems, Issues with motor skills, Abnormal physical development or functions, Inappropriate emotional reactions, Hypersensitivity to sensory stimuli, In some cases, autistic individuals can develop great skills in specific areas
See, 2012	Children with autism often are associated with behavioral problems such as: Becoming restless and fidgety, Exhibiting tendencies to touch and hit people, Being noisy (shouting or screaming), Exhibiting temper tantrums, Being inattentive, Non-compliance, Spaced out and body stiff.
Dominick et al. 2007	Features of autism may also include: The resistance of being touched, Ignorance of heat and cold, No sensation of pain, Fascination with sounds and tastes, Giggling and crying for no apparent reason, Absence of emotion and reactions, Self-injuries behaviors, Self-stimulatory behaviors
Meiriawan et. al. 2017, Watson et. al. 2015	Often associated with tantrums that is more likely to occur in public places, They release all forms of anger by crying hard, screaming, shouting, hitting, kicking, lying and rolling on the floor, running, biting themselves, throwing things and others, The behavior of temper tantrum indicates that autistic children feel frustrated, this is usually because of their desire is not fulfilled, This tantrum can last from 10 to 15 minutes, depending on the autistic children's current energy
Meiriawan et. al. 2017	Have difficult in communicating, Have difficult in addressing needs, Have difficult in controlling their emotion, Minimum eye contact, Repetitive behaviors Attention is easy to change, Show the temper tantrum behavior because of communication disability
Dillenburger, 2013	Difficult to understand other people's feelings, Difficult of being understood, Having concentration difficulties, Show aggression

Autism is a spectrum disorder and it can be found in all races, social status, religions and classes of people and can occur in any child and family (Audu & Egbochuku, 2010). Autism is believed was caused by a neurological disorder that affects the normal functioning of the brain, impacting the development in the areas of social interaction and communication skills (Gray, 2002). Unfortunately, the real cause of autism is still unknown and researchers suggest many causes theoretically and it has been reported that there is no medical cure or pharmaceutical treatment for autism (Dillerburger, 2013). Many have reported that the number of children with ASDs have increased over the past decade (Donald, 2002).

Although children with autism look like normal children (Jasni et. al. 2011) but they always exhibit distinctive characteristics (Gray, 2002). Features of autism are universal but vary from person to person (Gray, 2002). The common characteristics of children with autism are shown in Table 1.0.

Autistic behaviour as listed in table 1.0 might cause high stress level among parents of children with autism (Jiar and Xi, 2012). Parents with autistic children are more likely to experience greater risk for mental health problems than any other parents who have children with other disabilities (Donald, 2002). According to See (2011), the pattern of this behavior can be extreme and highly apparent or more subtle. It was reported that any behaviors associated with ASDs can range from mild to severe. It means that some autistic children are very severely affected while others are only mildly affected by ASDs.

Many research and media highlighted the increase in the rate of autism diagnosis (Jiar and Xi, 2012). According to See (2012), it is believed that in Malaysia, the number of children who have some form of ASDs may be more than 60,000 children. Negative implications and social stigmatization associated with autism persists in today's society because of lack of knowledge about this syndrome that exists in society.

4.1 Public Awareness and Attitude towards Children with Autism from Literatures

Individuals with disabilities such as autism sometimes suffer from certain stigma such as cues, stereotypes, prejudice, discrimination and segregation from the public (Edyvean, 2008). This was not supposed to happen since they also have the right to be treated equally in any aspect, especially in the fields of education and employment. Community should accept their existence with the open heart. Positive attitudes towards people with disabilities such as autism are very important to encourage interaction among autistic individuals and general public (Ryan, 2013).

A study conducted by Isabelle Durand-Zaleski et. al. (2012) found that although 95% of respondents recognized the name of autism, schizophrenia and bipolar disorders, however, less than 70% can report its specific characteristics. This study also indicated that most public attitudes and behaviour towards different disorders seem to be based on assumptions rather than knowledge or evidence (Isabelle Durand-Zaleski et. al., 2012).

There are several factors that can affect the attitudes of people toward individuals with disabilities. Among the factors highlighted by Cathryn T. Ryan (2013) in his study is the perceived causality of the disability, gender, age, education and social desirability. Source of information is also important to provide more accurate information about autism.

It was reported that most people in Britain think that individuals with mental illness deserve sympathy, and more than 80% of British people think that society need to be more tolerant to them. However, not all of attitudes towards mental illnesses are so positive. It is common that the mental illness of any kind such as autism will have certain stigma (Edyvean, 2008). People who could not understand them often see these children as selfish, slow and odd (Jasni et. al, 2011) and they are sometimes referred to as mentally retarded (Audu & Egbochuku, 2010).

Although public awareness has increased in recent years, much remains to be done to improve the general social understanding about ASDs. The increased understanding promotes the transition for people to see those with autism from mentally ill or dangerous to individuals with special needs (Danielle, 2012). Study conducted by Jasni (2011) discovered that there is a big lack of autism awareness among people in Malaysia. Something must be done to raise this awareness, in order to help reduce the level of stress and distress among parents of autistic children which is believed to be higher than parents without disabled children (Jiar & Xi, 2012).

5.0 METHODOLOGY

This preliminary study adopted the survey research design. The sampling technique adopted for this study is simple random sampling technique. Several public locations were randomly selected and these included commercial area near Bandar Seri Putra, Bukit Mahkota, Putra Jaya and other places within the Klang Valley. The respondents consisted of residents, staff or owners of the shops and the customers who come to visit the selected public places. This descriptive study was conducted by distributing 250 questionnaires to people in selected public places including shopping malls within the Klang Valley. From 250 sets of questionnaires, only 242 were returned in all fully answered.

To ensure that the survey instrument is simple and acceptable by the respondents in this study, the items in the questionnaire is limited to only 12 questions and it was written in Bahasa Malaysia and English languages. The questionnaire in this study consists of 2 parts: Part A was about the respondent's demographic profile and Part B contains questions to assess public awareness towards the characteristics of children with autism. Questionnaires were used as the instrument for the study to collect data and it is

done through face to face interaction or by distributing to people in certain places. SPSS was used to analyse the primary data.

6.0 ANALYSIS AND INTERPRETATION

From Table 2.0, it shows the demographic profile of all 242 respondents. Respondents between 18-60 age group have been chosen and most of them are in the age range 21-30. Out of 242 respondents, 140 were women. Most of respondents were Malay, Muslim and married. Degree holders (46) are mostly working as managerial staff, Master's degree holders (48) mostly worked as academician and others mostly non-managerial staff (60)

Table 2.0: Profile of Respondents

Demographic	Frequency & Percentage
	N=242
Male	102 (42.1)
Female	140 (57.9)
Age below 21 Years	40 (16.5)
Age 21 – 30	82 (33.9)
Age 31 – 40	65 (26.9)
Age 41 – 50	38 (15.7)
Age Over 50 Years	17 (7.0)
Single	98 (40.5)
Married	140 (57.9)
Others	4 (1.7)
PMR/SRP	9 (3.7)
SPM/STPM	92 (38.0)
Certificate/Diploma	45 (18.6)
Degree	46 (19.0)
Masters	48 (19.8)
Others	2 (0.8)
Academic Staff	30 (12.4)
Managerial Staff	51 (21.1)
Non-Managerial Staff	60 (24.8)
Self-Employed	21 (8.7)
Others	80 (33.1)
Muslim	222 (91.7)
Non-Muslim	20 (8.3)
Malay	220 (90.9)
Chinese	17 (7.0)
Indian	4 (1.7)
Others	1 (0.4)

Table 3.0 shows the breakdown of the respondents' backgrounds based on their answers to the question "Have you ever heard about autism?" Overall, it shows that 76.7% of respondents had heard about autism, while 21.5% had never heard the term autism and 5.8% are not sure about autism.

Table 3.0: Socio-demographic characteristics of sample know about the term autism

Socio-demographic variable	Frequency (n=242)		
	Yes	No	Not Sure
Gender:			
Male	69	28	5
Female	107	24	9
Age:			
Below 21	21	12	7
21-30	60	17	5
31-40	52	12	1
41-50	31	7	0
Above 50	12	4	1
Marital status:			
Single	59	27	12
Married	114	24	2
Others	3	1	0
Academic:			
PMR	3	6	0
SPM/STPM	51	30	11
Certificate/Diploma	31	11	3
Degree	43	3	0
Masters	47	1	0
Others	1	1	0
Occupation:			
Academician	29	1	0
Managerial	45	6	0
Non-managerial	36	22	2
Self-employed	9	6	6
Others	57	17	6
Religion:			
Muslim	171	40	11
Non-Muslim	5	12	3
Race:			
Malay	169	40	11
Chinese	4	10	3
Indian	2	2	0
Others	1	0	0

Table 4.0: The main source of information about autism selected by respondents

SOURCE	FREQUENCY	PERCENTAGE
TV	69	28.1
Radio	15	6.2
Friends	34	14.0
News paper	41	16.9
Conferences	6	2.5
Others	26	10.7
Do not know	51	21.1

Table 4.0 shows the main sources of information on autism selected by the respondents. It indicates that the television (TV) is the most preferred source (28.5%), followed by newspapers (16.9%) and the lowest is the conference (2.5%). Respondents who use the internet as their primary source of information, chose 'others' (10.7%) as their answer. Meanwhile, out of 242 respondents, 21.1% answered 'do not know' to represent respondents who did not know anything about autism.

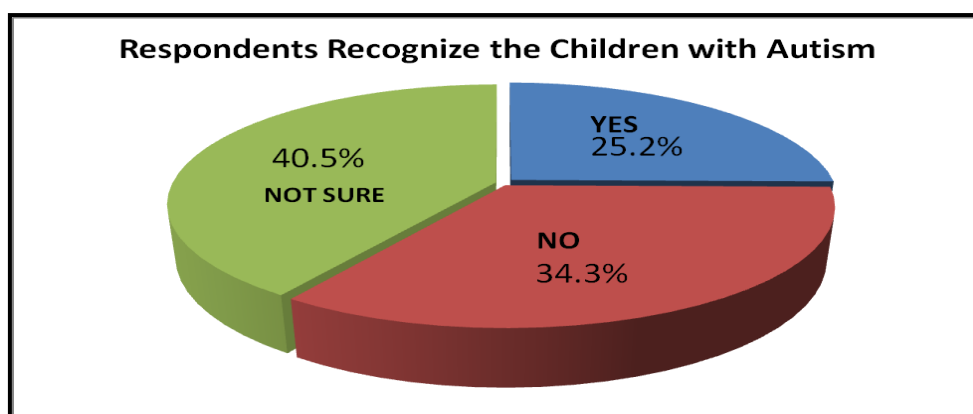


Figure 1.0: Respondents recognize the children with autism

On the question “Can you better recognize the children with autism?”, only 25.2% answered “yes”, the other (34.3%) respondents replied “no” and the rest give the answer “do not sure” (40.5%).

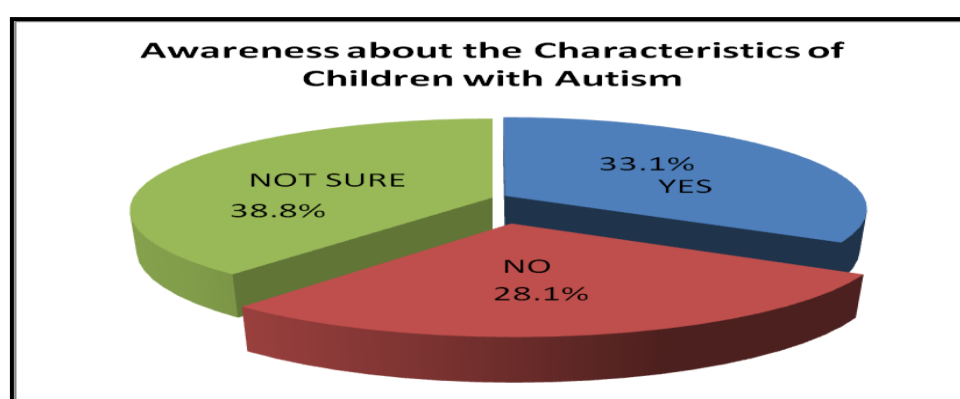


Figure 2.0: Awareness about the characteristics of children with autism

In response to the question “Do you know about the characteristics of children with autism?”, only 33.1% answered “yes”, 28.1% replied “no” and the other 38.8% are not sure about the autistic children's characteristics.

To determine whether the people of Selangor can really identify children with autism, as shown in Figure 1.0, only 25.2% of respondents answered “yes”. In the meantime, figure 2.0 shows that only 33.1% of respondents know the characteristics of children with autism. Others do not know exactly about the physical characteristics of children with autism. It is interesting to note that the number of responses to the answer 'not sure' is quite high. It indicates that people do not know the physical appearance and characteristics of the autistic children.

7.0 DISCUSSION AND SUGGESTIONS

This research paper presents the results of a study on public awareness in the state of Selangor towards the characteristics of children with autism. It was found in this study that, although 76.7% of respondents reported familiarity with the word autism (76.7%) but not all can describe the physical appearance of the autistic children. It means that, in fact most of the respondents did not know about the actual characteristics of autistic children. It also found that some of them think autism is similar to hyperactive children.

This study also discovered that there are still people out there who have never heard the word autism (21.5%). This study showed that only 25.2% of respondents could recognize children with autism and only 33.1% knew the actual characteristics of autistic children. Stated by Isabelle Durand-Zaleski et. al. (2012) in their study in France, awareness of autism only with its name, does not mean that they know everything about this autism spectrum. Meanwhile, a study conducted by Jasni (2011) also found that the majority of respondents did not understand about autism in general and how to recognize them. It is suggested that the lack of awareness among Malaysians can be solved by using ICT or multimedia learning (Jasni, 2011).

The result about source of information on autism spectrum selected by the respondents is quite similar to data analysed by Nahida Khan et. al. (2011) in their study on organ donation in Pakistan. From these two studies, it was found that the main source of information comes from television (TV). This study showed that 28% of respondents obtained information about autism spectrum from TV, about 16% obtained from newspapers, followed by friends (14%). The study also shows that many people do not prefer to choose the conference as their main source of information. This is probably because most of the respondents came from the age range 21-30 and were mostly working as non-managerial staff who may thought that the conference of autism is not important. Here, television can be considered as the best medium to use in educating public about children with autism and their characteristics. Information about autism on TV should contain the correct information and use the appropriate way to attract more people to watch and understand autism on TV. People's attitudes toward individuals with autism improved when they received information from formal sources (Ryan, 2013).

This study actually stimulated the respondents to know more about autism. Researchers realized that some of the respondents directly surf the internet to find information about autism after completing their questionnaires. With this findings, it is hoped that all parties involved will work together to increase public awareness and knowledge towards autism spectrum so that all negative view about autism will change to positive. The public awareness and understanding is also important in the formulation of public health policy and funding allocation (Selamat Widiasmoro Neni et. al., 2010).

All parties, including the health care team, clinicians, teachers, school workers, agents from outside support groups or foundations, families and the autistic individuals themselves must collaborate to figure out a better way to increase awareness, understanding and tolerance towards the individual with autism, to ensure the success of treatment for ASD and to provide the best life for them (Quirantes, 2009).

8.0 CONCLUSION

This study is a preliminary study to seek the awareness among people in Selangor towards the characteristics of children with autism. Overall, it can be concluded that there is a lack of public awareness towards the characteristics of children with autism among Selangor people. Even many people have heard about autism but they still do not really understand the nature of children with autism. Some of them even cannot recognize the physical appearance of autistic children.

Sometimes autistic children will do something that cannot be controlled by parents, especially when they are in public places. People other than parents, families or guardians of autistic individuals should be aware that autistic children tend to create behavioural problems unpredictably. Therefore, it is important to raise awareness among Malaysians about autism and their characteristics in the hope that people will come forward to help parents to cope with the stress associated with this autistic behaviour. All initiatives need to be done to help reduce the stigma experienced by autistic children and their families. A public-awareness program can also be designed to achieve certain objective such as to disseminate information about autism and to educate people about autism as a whole.

9.0 LIMITATIONS

There will be limitations in doing this research that need to be acknowledged. One of it, probably due to the limited literature related to awareness, knowledge and attitudes of public towards children with autism. Since this is only a preliminary study, therefore by this small sample size may not represent the whole population of Selangor. It is suggested that further studies need to be conducted to investigate the determinants that influence the attitudes and analyze the relationship between each determinant and the attitude of Malaysians towards children with autism and their characteristics.

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